

A Study of Care Giver's Burden in Parents of Children with Specific Learning Disability

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ABSTRACT

Current research findings have indicated that diagnosis of specific learning disability in a child is commonly experienced as having a devastating effect on parent's lives. Parents or care-givers are definitely the heart of the family; who not only has to deal with the issues associated with child's disability but also has to maintain the household. To date, a number of studies have demonstrated that caregivers are more vulnerable to develop mental and physical problems as compare to non-caregivers. The present study assessed and compared the family burden among the parents of children with specific learning disability and healthy controls. Family Burden Interview Schedule was administered on 50 parents of children diagnosed with specific learning disability from special schools in New Delhi and 50 parents of healthy controls. Statistical analysis was done using SPSS-16.0. The results revealed a high prevalence of burden in study group. Further in comparison, a significant difference was found between study group and healthy control group. Study group showed significant higher level of burden than healthy control group.

Keywords: *Specific Learning Disability, Care-givers, and Family burden*

Learning disability (LD) refers to a disorder that interferes with one's ability to store, process or produce information (Hornsby, 1994). Learning disabilities are seen in children as well as in adults. The impairment may be so subtle that it may go undetected throughout the life. These disabilities create a gap between the true potential and day to day productivity and performance. The learning disabilities is a generic term that refers to a heterogeneous group of disorders manifested by significant difficulties in the acquisition and use of skills such as listening, speaking, reading, writing, reasoning, or mathematical abilities. The skills are measured by standardized tests whose scores must fall substantially below the level expected from chronological age, intelligence, and age-appropriate education.

CAREGIVERS BURDEN

Caregiver burden is defined as, "a multidimensional response to physical, psychological, emotional, social and financial stressors usually associated with the experience of caring" (Kasuya, Polgar-Bailey, Takeuchi, 2000). Burden of care has two components namely

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subjective and objective burden (Hoeing & Hamilton, 1966). Objective burden includes measurable effects such as economic burden, caregiver's loss of work, social and leisure activities, household disruptions such as child care, restrictions on relationships within and outside the family etc. Subjective burden is mainly the psychological sufferings of the caregivers themselves and is experienced by them such as depression, hatred, uncertainty, guilt, shame, embarrassment etc. (Ravindranadan & Raju, 2007). Irrespective of the level of disability; it is for sure that caregivers have to cope with their special needs and therefore disability in children are not only problem for affected children, but in real sense they are 'family disease'(Witt, et al., 2003).

While raising a child with chronic condition, parents experience psychological stress and disappointment when their child does not meet their hopes and expectations (Barnett, et al., 2003). Caregivers experience depression, burden, less social support, and less coping resources than non-caregivers (Vitaliano, et al., 2002). As a general agreement, child with learning disability can impose psychological problems, social issues, and lifestyle restrictions that can affect quality of life of the caregivers and family members, who also bear the considerable indirect costs of patients' disability. Its strong impact, make it of extreme importance to investigate its mechanisms and find new avenues towards its potential prevention and treatment for caregivers. It can be assumed that the negative consequences of burden on caregivers may harm their care giving effectiveness, whereas experiencing subjective gains and satisfaction may enhance their caregiving ability. Hence present study is planned to assess the degree of caregiver's burden among the parents of children diagnosed with specific learning disability and to compare them with normal controls in Indian setting.

METHODOLOGY

A case control study, to assess the caregiver's burden among parents of children with specific learning disability and normal control group.

Tools Used

The following tools were used for the present study:

- **Socio-demographic Performa:** A special performa designed for this study was used to gather socio-demographic details about the subjects.
- **Family burden interview schedule:** Family Burden Interview schedule developed by Pai and Kapur, (1981) was used to assess family burden. This scale measures objective aspects of burden and it contains six general categories of burden, each having two to six individual items for further investigation. Subcategories include: Financial burden, Effects on family routine, Effects on family leisure, Effects on family interaction, Effects on physical health of family members and Effects on mental health of other family members.

Procedure

Total of 100 parents of children were assessed. 50 parents were recruited from the special schools in New Delhi and who had children diagnosed with Specific Learning Disability. Another 50 parents of healthy children were recruited from the localities adjoining the special schools in New Delhi.

RESULTS AND DISCUSSION

The study is exploratory in nature so the suitable statistical package for social science (SPSS: version 16.0) was used.

Table 1: Socio-demographic details of the study and control group

Variable	Item	Study Group	Control group	
			(N=50) N (%)	(N =50) N (%)
Age	Mean± SD	34±7	30.92±3	
Gender	Male	8 (16%)	—	
	Female	42(84%)	50(100%)	
Residence	Urban	45(90%)	28(56%)	
	Rural	5(10%)	22(44%)	
Marital status	Married	50(100%)	50(100%)	
Occupation	Unemployed	7(14%)	1(2%)	
	Housewife	40(80%)	43(86%)	
	Salaried	2(4%)	5(10%)	
	Business\self employment	1(2%)	1(2%)	
Religion	Hindu	49(98%)	49(98%)	
	Sikh	1(2%)	1(2%)	
Education	Illiterate	20(40%)	1(2%)	
	< Secondary	22(44%)	28(56%)	
	< Secondary	8(16%)	21(42%)	
Family type	Joint	20(40%)	27(54%)	
	Nuclear	30(60%)	23(46%)	

Table 2: Significance of Mean Difference in Study Group and Control Group on family burden scale

Variables T	Study Group	Control Group
	(N=50) (Mean ± SD)	(N=50) (Mean ± SD)
Financial burden	6.74±1.68	0.68±.51
24.290*		
Financial burden	6.74±1.68	0.68±.51
24.290*		
Disruption of Routine family Activity	2.48±.88	0.30±.46
15.418*		
Effect on Physical health of others	2.42±.94	0.58±.49
12.132*		
Effect on mental health of others	7.80±1.86	0.10±.30
8.852*		
Disruption of family leisure	7.86±1.88	0.14±.35
28.478*		
Disruption of family Interaction	2.56±1.12	0.22±.41
13.755*		
Subjective burden	4.88±1.27	0.16±.37
25.193*		
Total	31.80±6.46	2.18±1.24
31.802*		

*p<.01

DISCUSSION

In present study parents in study group perceived high level of burden. This is corroborating with the findings of a study done by Sahu, et al., (2018) who studied the perception of families of children with SLD. Five focus group discussions (FGDs) including 30 parents of children with SLD aged between 8 and 14 years were carried out. Each group composed of five – seven participants. A format to guide FGDs was made to bring uniformity across groups. The transcripts were analyzed using the content analysis method to extract key conceptual themes. The parents showed lack of conceptual knowledge with regard to the SLD symptomatology as well as proper guidelines to deal with their child's problem. They displayed negative attitudes and reactions toward their child's diagnosis of SLD, such as rejection, denial, over-protection, and loss of hope. Their care giving was also perceived to place physical, personal, social, financial, and emotional burden by the majority of parents. The study highlights the experiences of parents dealing with SLD in terms of their inadequate knowledge, adaptation difficulties, and burden. The findings also reiterate the need to focus on family perspective and experiences when working with a learning-disabled child. Various supportive strategies are required to empower families, which would help alleviate their burden. Moreover, parents' training to strengthen child's learning skills is also warranted.

While raising a child with chronic condition, parents experience psychological stress and disappointment when their child does not meet their hopes and expectations (Barnett, et al., 2003). As a general agreement, child with specific learning disability can impose psychological problems, social issues, and lifestyle restrictions that can affect quality of life of the caregivers and family members, who also bear the considerable indirect costs of patients' disability. Simon & Easvaradoss, (2015), who found low quality of life and high parenting, stress among parents whose children have Specific Learning Disability. This study highlights that while managing specific learning disability, parental aspects also need to be addressed to provide wholesome management for the child. Addressing and managing parental stress will also improve quality of life. Both fathers and mothers of children with Specific Learning Disability should be given assistance to improve their wellbeing. A parental counseling module incorporated into the management program for Specific Learning Disability will be beneficial. Sessions addressing parental anxiety, depression, self-esteem, guilt or self-blame in addition to psycho-education focused on empowering parents to effectively manage.

In another study by, Heykyung Oh & Eun-Kyoung Othelia Lee, (2009) examined caregiver burden and social support perceived by mothers raising children with developmental disabilities in South Korea. Mothers residing in the metropolitan areas of Seoul ($n = 181$) responded to the mail survey with a 56.6% response rate. Respondents expressed a high level of overall burden, particularly in financial domains. Greater subjective caregiver burden for these mothers was associated with increased disability-related costs; maternal factors such as being younger and having higher educational attainment; and less social support. Extra cost related to disabilities was the strongest predictor of increased caregiver burden. Findings indicate that social support can reduce this burden.

Limitations

Since, the study sample was small; results cannot be generalized to a larger population. A prospective study with a larger sample size and objective data evaluation would be ideal.

CONCLUSION

Half of parents taking care of children with disabilities experience psychological distress in India. This study encourages health care providers to pay more attention to the mental health of CGs, especially for CGs having health problems of their own, activity restrictions, or low social support and for CGs of lower income families. Further research should examine more detailed information regarding the disease and disability of disabled children, their medical service use, and the quality and quantity of the CGs' social support to improve the method of providing supporting service for both children with disabilities and their families. In our country where we have limited resources and it is high time that we should realize that we may not develop holistic health of the patient if the caregivers are overburdened. So treatment providers should also shift their focus to the mental health of care givers too along with that of individuals with specific learning disability.

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Conflict of Interest

The author(s) declared no conflict of interest.

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